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Living with Dignity: A Pilot Study Implementing Dignity Therapy with Allogeneic Blood or Marrow Transplant Recipients

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Living With Dignity: A Pilot Study Implementing Dignity Therapy

With Allogeneic Blood or Marrow Transplant Recipients

A DOCTORAL PAPER

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DOCTOR OF PSYCHOLOGY

BY

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Abstract

Dignity Therapy is a relatively novel therapeutic intervention designed to address psychosocial and existential distress among those facing life threatening circumstances. This narrative psychotherapy approach invites patients to reflect and speak about issues that are most important to them and hopes to elicit feelings of purposefulness and autonomy, characteristics that are typically waning when nearing end of life. Dignity Therapy consists of a ten question semi-structured interview designed to integrate themes of accomplishments and sources of pride, things that may feel unsaid, and/or particular lessons or wisdom that the patient hopes to pass on to loved ones. The interview is transcribed, edited with the patient, and provided as a typed “generativity document” to the patient. Dignity Therapy has been empirically validated to lessen symptoms of existential distress in various terminally ill populations. In this pilot study, the dignity therapy intervention was implemented with five members of a novel patient population; those who have undergone an allogeneic blood or marrow stem cell transplant following a diagnosis of blood cancer. These participants engaged in the Dignity Therapy intervention and then filled out a brief feedback questionnaire. It is our hope that this pilot study will serve as a feasibility study to identify if this intervention will be acceptable and meaningful to this novel patient population.

Keywords: Dignity Therapy, bone marrow transplant, allogeneic, psychosocial oncology

With Allogeneic Blood or Marrow Transplant Recipients

Introduction

When researching the topic of dignity, I came across countless personal anecdotes on the subject in the form of blogs, posts, memoirs, and articles. The content I read always seemed that it was coming straight from the heart; from what felt like raw, first hand experiences where personal human dignity was absent. People wrote of violations of dignity in the form of gender inequity, poverty, and societal ignorance. They argued that dignity itself was more valuable than wealth and even happiness. And certainly there is a large body of literature about dignity being cracked and splintered at the end of life. The great American author Laura Hillenbrand wrote in her book *Unbroken: A World War II Story of Survival, Resilience, and Redemption* that, “Dignity is as essential to human life as water, food, and oxygen. The stubborn retention of it, even in the face of extreme physical hardship, can hold a man's soul in his body long past the point at which the body should have surrendered it” (p. 198). Although as health care providers we may not hear our patients speak of dignity or at least use this word explicitly, we are tasked with attuning to the evidence of loss of dignity that we must assume has the potential to creep in and weigh heavily on our patients.

Literature Review

The importance of dignity in life threatening circumstances has emerged from research within the fields of euthanasia and physician assisted suicide and has been spearheaded by Dr. Harvey Max Chochinov. Early work by van der Mass and van Delden (1991) caught the

attention of Dr. Chochinov. It revealed that 57% of all patient requests for euthanasia in the Netherlands, where this has been in practice for several decades, were made for reasons of loss of dignity, more than any other possible reason including pain (46%), dependence on others (33%), and tiredness of life (23%). It is this connection between sense of dignity and will to live that spurred interest in better understanding how the western medical model, which has been criticized for lacking compassion and being outcomes-driven to the point of sacrificing human-centered care, may be creating fractured dignity in patients and thus, contributing to poorer health outcomes (Chochinov et al., 2012). Chochinov and his team of researchers have been devoted to understanding the concept of dignity, particularly within vulnerable populations, for over 20 years, with the goal of defining the term operationally and investigating possible ports of intervention to improve a sense of dignity in terminally ill patients or those with a life-threatening illness.

The dignity therapy model emerged from research with patients close to death (Chochinov et al., 2002). Over a four-year period, 213 patients with end-stage cancer registered in palliative care programs were asked to rate their dignity on a 7-point scale (0= no sense of lost dignity, 1= minimum, 2= mild, 3= moderate, 4= strong, 5= severe, and 6= extreme sense of lost dignity). Patients also completed a symptom-distress scale, a pain questionnaire, the index of independence in activities of daily living, a quality of life scale, a brief battery of self-report screening measures of desire for death, anxiety, hopelessness, and will to live, and ratings of social support. The research team found that there was about an equal split between patients who reported their sense of dignity to be strong or intact and patients who indicated that they had at least some dignity related concerns. Patients who reported experiencing significantly fractured dignity (7.5%) were more likely to be hospitalized, younger, and to indicate a desire for death,

and that they felt depressed, hopeless, or anxious. Overall, the researchers suggested quality of life ratings were significantly lower in those with a fractured sense of dignity than in those whose dignity was intact.

Following this research, the team began to grow curious about delving deeper into the construct of dignity, defining it operationally, and understanding the experience of dignity related concerns more fully. In another study, 50 patients who were nearing death were asked to answer a semi structured set of questions explaining their understanding of dignity, for example, “What does dignity mean at this stage in your life?”, “Can you recount instances when your dignity has been undermined?”, and “Can you remember situations when you felt your dignity was particularly supported?” (Chochinov et al., 2002). What materialized was a developing “Model of Dignity in the Terminally Ill”. It appeared that there were three major sources of influence identified to be of concern related to dignity among these patients that are outlined in Figure 1 below. These sources included “Illness-Related Concerns” or factors that derive from the illness directly and elicit physical and psychological responses including decreased mobility, inability to self-regulate, etc.; “Dignity-Conserving Repertoire” including the myriad of psychological and spiritual factors influencing sense of dignity such as role preservation, hopefulness, etc.; and “Social Dignity Inventory” which involves external factors such as social environment that affect sense of dignity.

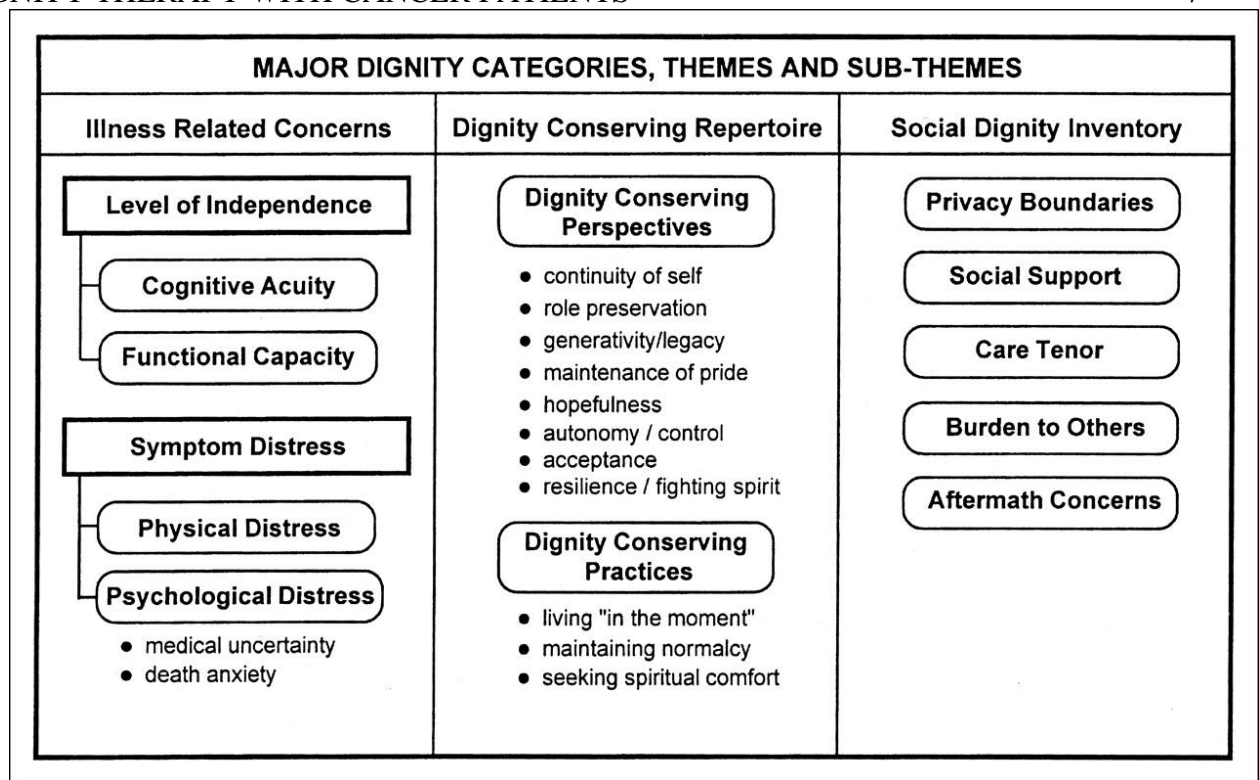


Figure 1. Model of Dignity in the Terminally Ill (Chochinov, 2012, p. 9).

“Illness-Related Concerns” can be further broken down into two subthemes, level of independence that is both related to cognitive acuity and functional capacity, and symptom distress that includes both physical and psychological distress. The “Dignity-Conserving Repertoire” is also comprised of two important distinctions, that is, both the perspectives and practices of dignity. The perspectives of dignity conservation, or the subjective landscape for experiencing dignity, are manifold. As seen in the table above, Chochinov highlights eight specific subthemes that compose these possible perspectives which include: continuity of self (the extent that patients are able to maintain their sense of individualism and personhood); role preservation (the extent to which the patient can maintain previous roles and responsibilities); generativity or legacy (the extent to which the patient feels that he/she can provide guidance for the next generation and can transcend death); maintenance of pride (the extent to which the

patient feels that he/she can maintain a positive self-regard or self-respect); hopefulness (the extent that patients feel connected to notions of meaning and purpose); autonomy/control (the extent to which one is able to carry out various functions, notably activities of daily life and self-care); acceptance (the extent to which the patient is able to adapt to changing health circumstances); and resiliency and fighting spirit (having internal strength to overcome obstacles). Dignity conserving practices, on the other hand, are defined as behaviors and activities that foster the ability to manage changing health circumstances. Examples of these may include living in the moment, maintaining a sense of normalcy, and seeking spiritual comfort. Finally the “Social Dignity Inventory” highlights the many relevant relationship issues and dynamics that may influence a patient’s sense of dignity. The five elements that comprise the “Social Dignity Inventory” include: privacy boundaries, particularly within a hospital setting, but also at home with caregivers with regard to intimate dependencies; social support, or helping the patient feel heard and not abandoned; care tenor, or the tone of care that health care providers convey to patients and families and how patients perceive themselves to be seen by their health care providers; burden to others; and aftermath concerns, or issues related to the wellbeing of those the dying patient will leave behind. It was determined that when these factors, the “Illness-Related Concerns”, “Dignity-Conserving Repertoire”, and the “Social Dignity Inventory”, are threatened and one experiences a decline in health, confrontation of the end of one’s existence, and withdrawal from social networks, the patient will most surely experience psychosocial or existential distress (Chochinov et al., 2002). Loss of dignity for people reaching the end of their lives is associated with high levels of psychological and spiritual distress and loss of the will to live. Thus, an intervention with the goal of improving dignity in these populations must attend to these important elements.

It was based directly on the “Model of Dignity in the Terminally Ill” that Dignity Therapy was created with the intention of mitigating insults to dignity in patients nearing end of life. Chochinov (2012) writes, “In essence, patients taking part in Dignity Therapy are invited to engage in conversations, addressing issues or memories that they deem important or that they want recorded for the sake of those loved ones who will outlive them” (p.42). This narrative approach welcomes patients to reflect and speak about issues that are most important to them and to discuss wisdom learned and sources of pride throughout their lives. In conjunction with this, the conversations are audio-recorded and transcribed in the effort to promote generativity and the therapist works with a tenor of genuine compassion, helping the patient to feel valued and honored, affirming the patient’s sense of personhood in recalling important memories and life lessons, allowing for the opportunity to be heard and listened to by the therapist, and providing a document for the patient to bequeath to a loved one.

Before reviewing some of the relevant literature, I will first take a moment to expound upon the details of this therapeutic approach. The Dignity Therapy protocol is outlined by McClement, et al. (2007) and includes eight steps. First, the treatment provider must identify mentally competent patients who are either terminally ill or facing life threatening illness who wish to take part in Dignity Therapy. Second, the patient is guided through a semi-structured Dignity Therapy interview by the therapist using a standard question protocol. This protocol typically includes questions such as “Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important?” and “What have you learned about life that you would want to pass along to others?” (Please see Appendix A for the complete list of questions). Other themes that may be integrated into the interview include multiple roles the patient may have had throughout his/her life, sources of accomplishment, things that may feel

left unsaid, and/or hopes for the patient's sense of legacy. These interviews are typically carried out over one to two sessions that are about an hour in duration. The third step in the Dignity Therapy protocol involves transcribing the interview, which is completed within two to three days of the final interview session in the effort to provide the final transcribed document in proximity to the interview. Fourth, transcripts are edited by the therapist to convert what is a dialogue format into a more polished narrative. During the fifth step, the manuscript is read aloud to the patient and he/she is invited to edit the narrative at this time to his/her desire. This process is carried out with the intention of correcting any unintentional errors made by the interviewer and/or transcriber, of ensuring that the narrative is comprehensive, and to provide the opportunity for the patient to hear his/her story read aloud to them. Any necessary corrections are completed within 24-48 hours in the sixth step. Then, in the seventh step, the patient is provided a hard copy of their generativity document and finally, and in the eighth step, the patient may share or bequeath the document to loved ones of his/her choosing if they wish to do so. These steps have been validated in previous research, which I will now discuss.

Previous Research on Dignity Therapy

Early research by the Chochinov research team (McClement et al., 2004) noted that the importance of palliative care being philosophically rooted in an acknowledgment of the inherent dignity of the individual had been expressed in the literature for years, but at that time, there was a paucity of work regarding dignity in the face of serious illness or at end of life. The first clinical trial of Dignity Therapy (DT) was published in 2005 and demonstrated the utility and impact of engaging in the DT intervention with a cohort of 100 patients in Australia and Canada (Chochinov et al., 2005). Patients were mostly in the end-stages of cancer with a median survival of 51 days from the first point of contact to the time of death. Of the 100 patients who completed

the DT intervention, 91% reported feeling satisfied with the therapy, 86% reported that the intervention was helpful or very helpful, 76% indicated that it heightened their sense of dignity, 68% indicated that it increased their sense of purpose, 67% indicated that it heightened their sense of meaning, 47% indicated that it increased their will to live, and 81% reported that it had already helped, or would help their families (Chochinov et al., 2005). It was considered that this therapeutic approach was capitalizing on tenants of life-review or Intersubjective therapies, which have been shown to have a statistically and clinically significant effect on symptoms of depression comparable to other treatments including antidepressant medications and cognitive behavioral therapy (Boohlmeiger et al., 2007), while also expanding the scope of these practices by emphasizing components of autonomy and legacy.

But what about the impact on the caregivers? After all, one of the primary functions of producing the generativity document is to provide a transitional object for the family and for the patient's experience to be better understood by their support network. McClement et al. (2007) studied the caregiver's perceptions of the DT intervention and revealed that 95% of patient's family members reported that DT helped the patient; 78% reported that it heightened the patient's sense of dignity; 72% reported that it heightened the patient's sense of purpose; 65% reported that it helped the patient prepare for death; 65% reported that it was as important as other aspects of the patient's care; and 43% reported that DT reduced the patient's suffering. It appeared that patient's family members felt as though their loved ones were also benefitting from the intervention and felt as though their involvement in the protocol had significantly helped to reduce suffering.

Over time, hundreds, if not thousands, of patients have taken part in the DT intervention. With such a wealth of rich narrative material gathered at such an important phase of life, what

can we learn from the content of these stories? Research by Hack et al. (2010) aimed to better understand the content of DT interviews, or in other words, what mattered most to dying patients. 50 DT transcripts were randomly drawn from previous research and were coded and analyzed using a grounded theory approach. Notably, the transcripts suggested that DT served to provide a safe environment for patients to recall meaningful aspects of their lives with a therapeutic witness in such a way that patient's core values became evident. Some of the most commonly expressed values apparent throughout the transcripts included family, enjoyable activities, caring, a sense of accomplishment, true friendship, and richness of life experiences.

Continued research by Chochinov et al. (2011) was conducted to determine if Dignity Therapy could mitigate distress and/or bolster life affirming experiences for patients nearing death. Data was collected via a blind, multi-site randomized controlled trial where participants were assigned either to a DT intervention group or a Client Centered Care intervention group, which is essentially a standard practice here-and-now focused psychotherapeutic approach. There were 326 participants who were patients receiving hospital or community (either hospice or home) palliative care. Outcome data included information on physical functioning, spiritual well-being, anxiety and depression, perceived sense of dignity, and quality of life. This research highlighted the important clinical application of Dignity Therapy for distressed patients nearing death. Those who participated in the DT intervention were significantly more likely to report the experience as helpful, to have improved quality of life, to have a heightened sense of dignity, to have an increase in appreciation from their families. This research also showed that DT was significantly better than both client-centered care and standard palliative care in being helpful, improving quality of life, increasing sense of dignity, and helping patient's families

With a solid foundation of empirical data building the case for the relevance of DT in the oncology population, researchers began to wonder if the intervention may bear utility in additional populations, most notably, within the elderly population, as dignity enhancing interventions and bereavement support may be increasingly relevant as the general population ages. Similar to an oncology population, the elderly tend to have multiple serious health problems and can experience a range of physical, psychological, and spiritual distress. Hall et al. (2011) sought to investigate the potential efficacy of DT outside of the oncology population, although with a medically vulnerable and potentially imminently dying population nonetheless. 60 older people in care homes underwent the DT intervention and outcome data revealed significance for patients feeling that DT would be helpful to families and that it aided in reducing dignity related distress. Goddard et al. (2012) investigated the views and experiences of care home residents' family members on DT. 14 family members of residents who had received DT engaged in semi-structured interviews and qualitative data was analyzed using a framework approach. Results indicated that DT had helped residents to positively reappraise aspects of their lives, that family members were satisfied with the generativity documents, and that the residents had enjoyed the process of creating the document and handing it down to the family. They also noted that they recognized the importance of their family member having the opportunity to relate on a more intimate level with the therapist conducting the DT, which was increasingly rare given the demands of the care staff, thus emphasizing the value of the therapeutic relationship even in this very brief of therapies.

Although these data highlighted the ample potential benefits of Dignity Therapy, the underlying process of these various improvements remained unknown. Hall et al. (2013) sought to explore patient's perceptions of the benefits of Dignity Therapy in a qualitative study where

patients were interviewed regarding the seven elements of the dignity-conserving repertoire discussed above. Three cancer patients with the highest levels of dignity-related distress as measured by the Patient Dignity Inventory were assessed at baseline, and at one and four weeks after completion of the intervention. This study suggested support for five of the seven themes from the model underlying Dignity Therapy including generativity, continuity of self, maintenance of pride, hopefulness, and care tenor, or, as previously described, the tone of care that health care providers convey to patients and families and how patients perceive themselves to be seen by their health care providers. Among these five themes, generativity was proven to be most salient in providing a sense of benefit to these patients. The authors note that the Dignity Therapy document, or generativity document, is in and of itself a physical manifestation of exerting influence and transcending death for the patient (Hall, 2013). This may involve leaving something behind that identifies the patient's accomplishments and connections to life and/or providing a medium to say things that patient's felt unable to say directly to people and would have therefore been left unsaid.

Researchers continued to broaden the understanding of the impact of DT on ameliorating depression and anxiety in more severely depressed, terminally-ill patients. Juliao et al. (2013) aimed to determine the influence of DT on symptoms of depression and anxiety in patients with known high levels of psychological distress and who faced life-threatening disease. 60 terminally ill patients were randomly assigned to either a DT plus standard palliative care or just standard palliative care group. Patients were assessed at baseline, day four, day 15, and day 30 post intervention using the Hospital Anxiety and Depression Scale. Results indicated that baseline characteristics were similar across groups, and that those in the DT intervention group showed a significant decrease in depressive symptoms at day four and day 15, but not at day 30, as well as

a significant decrease in anxiety at each of the follow up visits. Therefore, DT appeared to have a longer lasting effect on symptom reduction with anxiety and a shorter term beneficial effect on depression, although both the reduction of anxiety and depression were sustained beyond the time of therapeutic engagement. The researchers suggested that perhaps increasing the number of follow up visits with the DT therapist would be sufficient in maintaining these symptom reductions. Overall, the researchers noted that by “allowing patients to remember, speak about their past, and share important reflections, DT brings these special moments to the present, reaffirming a sense of meaning and purpose” (p. 488).

While there appears to be a significant amount of knowledge of factors affecting personal dignity of patients nearing death, less is known about how patients *living with* a serious disease understand and experience dignity. Using a similar method to the ground work employed by Chochinov and his team, researchers worked to develop a conceptual model of dignity that highlights the process by which living with a serious illness can impact dignity (van Gennip, Pasman, Oostervelf-Vlug, Willems, & Onwuteaka-Philpsen, 2013). In-depth, qualitative interviews were conducted with 34 patients affected either by cancer, early stage dementia, or severe chronic illness. Questions were intended to be open-ended and included topic areas such as “What is your personal understanding of dignity?” and “At the moment, do you feel dignified and why, or why not?” Based on the qualitative analysis, these researchers proposed a two-fold model of dignity specifically associated with the illness-related portion of Chochinov’s model. They suggested that illness related conditions seemed to affect patients’ dignity *indirectly* instead of directly by influencing the way patients perceive themselves when they are living with an illness for a sustained period of time. This self-perception included three unique domains that could potentially impact their experience of dignity which were: the individual self, or the

subjective experiences and internally held qualities of the patient such as identity and self-awareness; the relational self, or the self within reciprocal interaction with others including the ability to fulfill social roles, be independent, not feel like a burden, etc.; and the social self, or the self as a social object in society at large, including stigmatization or marginalization based on health status. The researchers explained that the experience of chronic and serious illness often involves frequent confrontation with the realities of the deterioration of the body, loss of functional ability, and dependency on others (van Gennip et al., 2013). Given these important factors of dignity that are distinctively impacted in the population living with serious illness, it is clear that living with dignity following diagnosis of a serious illness is worthy of attention as well.

Relevance to BMT Population

This research study proposed to pilot the Dignity Therapy intervention with members of the patient population diagnosed with blood cancers and who have undergone allogeneic blood or marrow transplant (allo-BMT), a novel population for this intervention. Patients who undergo blood or marrow transplants face one of the most stressful treatments in modern cancer care (Heinonen et al., 2005). Although allo-BMT may be potentially lifesaving for this population, the treatment process can bring with it significant complications including acute or chronic graft-versus-host disease, organ toxicity, osteoporosis, infections, secondary cancers, infertility, reduced quality of life, and functional limitations (Pidala, Anasetti, & Heather, 2009). In addition to subsequent physical complexities of allo-BMT, there are many potential psychosocial effects including decline in self-concept, feelings of helplessness, strained relationships, threat of death, and overall psychosocial distress (Beanlands et al., 2003). Research indicates that over 25% of

patients who undergo allo-BMT report continued significant depressive symptoms and perceive a significant decrease in social support throughout the first year post-transplant (Jenks Kettmann & Altmaier, 2008). What might be contributing to this psychosocial profile post transplantation? Earlier research in this area aimed to investigate the patient's experience at various stages after bone marrow transplantation. In a study where 125 BMT patients filled out questionnaires measuring domains including quality of life, functional limitations, psychological distress, anxiety, depression, self-esteem, and health locus of control at time points prior to BMT, one month-post discharge, and at six months, one year, and three years after BMT, researchers found that serious limitations across these spheres were experienced up to three years after the transplant by over 34% of the population (Broers, Kaptein, Cessie, Fibbe, & Hengeved, 2000). Specifically, they indicated that anxiety and general psychological distress were measured at its highest right before transplantation and then reduced afterwards. Functional limitations were the most enduring area of suffering, where 26.3% of patients were limited in at least five of the 11 functional areas measured by the Functional Limitations Battery three years post-transplant. The researchers also found that high percentages of patients appeared to be experiencing depression according to the SCL-90-R (25% scored high or very high); however, these rates may overestimate true depressive symptoms given the overlap in suffering BMT patients experience related to decreased physical capacity (i.e. decreased appetite, lower energy, decreased sexual interest, etc.). Ultimately, this cross-sectional data showed that although general quality of life may not return to that of pre-transplant in this patient population, it does appear to return to acceptable levels for most individuals. However, prevalence rates of psychiatric morbidity are generally higher in BMT recipients than in healthy subjects and a significant group of people suffer from psychological distress years following transplant.

Research has also explored the impact of BMT on the caregiving population as those who undergo an allo-BMT must have a caregiver with them 24 hours per day, seven days per week, for a period of typically 100 days following the transplant, placing the caregiver in a position where they are vulnerable to burnout and psychological distress. A study was conducted in which 40 patients and 39 caregivers were assessed prior to BMT using standardized self-report measures (Siston et al., 2001). Researchers found that 35% of patients reported significant problems of intrusive stress responses and 25% of patients reported difficulty with avoidant stress responses on the Impact of Events Scale (Christianson & Marren, 2013). 25% of patients also reported clinical levels of psychological maladjustment on the Psychosocial Adjustment to Illness Scale and had greater problems than those who had already undergone a BMT. Caregivers appeared to indicate similar distress levels to the patients; however, they reported more impairment in family relationships than patients did. This research highlights a number of important factors on the BMT patient's general psychological wellbeing. First, a distress mitigating intervention may be of benefit to the caregiving team in addition to the patient. And second, that the psychosocial impact of the BMT process may be influenced by the pre-BMT experience.

A study in 2005 conducted by Heinonen et al., utilized concept mapping to identify perceived stressors among 109 allo-BMT recipients who were a minimum of four months post-transplant. From most to least severe, the stress areas were identified as change of life and impact of treatment such as experiencing shock at becoming ill, side effects such as lack of appetite and vomiting, family-related stress such as fear of the future and well-being of family, treatment outcome and physiological status such as nervousness related to blood counts and weakened physical condition, other concerns such as conflicting thoughts over the transplant process, stress

related to medical staff such as hurried nursing staff, fear of death including experiencing extreme loneliness, and negative social support including feeling burdensome to others. The researchers suggest that interventions should therefore be targeted at these stressors that are most critical to the patient's wellbeing and that as health care professionals, we should be aware of the breadth of potential stressors impacting this vulnerable patient population.

The experience of long-term survivorship of allo-BMT patients has also been explored by researchers as these critical areas of psychosocial stressors can significantly affect quality of life for years following transplant. In particular, researchers have aimed to better understand more than just the medical complications that may prevent a full restoration of health after allo-BMT (Norkin, Hsu, & Wingard, 2012). Importantly, they note that the majority of allo-BMT recipients anticipate a return to pre-illness functioning, and that failure to meet this expectation may result in decreased psychological adjustment following transplant, coupled with physical recovery typically occurring long before psychological recovery or even one's ability to return to work. In general, these researchers highlighted multiple studies indicating that there is a significant decline in quality of life in the early post-transplant period with gradual improvement over time. A 2004 study by Syrjala et al. suggested that at three and five years post-transplant, only chronic graft versus host disease (GVHD) was associated with an increased risk of depression and delayed return to work. Despite this, they note that transplant recipients have been reported to show prevalence of psychiatric diagnoses rates that are more than double that of the general population, including one study by Widows, Jacobsen, and Fields (2000) that showed that 5% of BMT survivors met diagnostic criteria for post-traumatic stress disorder (as cited in Norkin, Hsu, & Wingard, 2012, p. 106). In addition to psychological distress, researchers noted that problems with memory disturbances and cognitive difficulties are also frequently reported by allo-BMT

survivors, which are problems often correlated with increased emotional distress, low self-esteem, and suboptimal quality of life.

Since we know that insults to the experience of dignity are the primary motivating factor to hasten death among the terminally-ill population, and that dignity is also seriously threatened from multiple angles during the experience of *living with* a serious illness, it is likely that the BMT patient population has a high percentage of those suffering from fractured dignity as well. The period of survivorship from BMT is unique in that it holds both the threat of mortality and the attempt to return to normalcy. In other words, the seriousness of illness is uniquely situational. Additionally, the BMT patient population is one that often continues to live at home or at least with a caregiver in an outpatient environment for a substantial duration of their treatment. Therefore the relational and societal self are key components in defining their sense of dignity. Given that approximately 40-80% of allo-BMT patients become long-term survivors (Storb, 2003), and given the complex and prolonged nature of this treatment process, it is imperative that we investigate treatment methods that may contribute to overall psychosocial adjustment in this population.

It has been suggested that patient's subjective appraisals of disease and treatment can be more important than the external objective characteristics of illness in affecting psychological distress (Heinonen, et al., 2005). Empirically identifying these subjective appraisals, can, however, prove to be challenging, when the domain under investigation is so unknown and likely complex, such as in the case of exploring the concept of dignity. Qualitative measures provide the opportunity to help a group under study to describe its perceptions of any topic of interest and can ultimately provide a method that can be used to identify domains that are difficult to operationalize. It is because of these defining features that we chose to analyze and interpret the

data collected through this research project primarily by utilizing a modified qualitative analysis based on the Consensual Qualitative Research method, which will be outlined in greater detail within the Methods section of this paper.

BMT is increasingly being used as a high-risk but successful treatment for various hematological diseases and as the procedure has become more sophisticated, mortality rates have decreased. The current body of research for Dignity Therapy in populations other than BMT links participation in a Dignity Therapy intervention with a decline of psychosocial distress from feelings of purposelessness, decreased perception of dignity, and overall poor self-concept. It was our hypothesis that similar benefits may be seen in a blood and marrow transplant population who have undergone an allo-BMT. Attention to dignity-related concerns earlier in the transplant process may both diminish future concerns the patient may have regarding suffering an undignified death and help refocus the BMT survivor on living after transplantation.

Methods

Study Design

This research study was a pilot project using both qualitative and quantitative outcome measures and was a descriptive field study design.

Setting

The recruitment and research visits for this single-center study occurred at a large metropolitan medical center, which conducts about 100 allogeneic transplants per year.

Recruitment

Any patient treated with allo-BMT who was at least 60 days post-transplant, who was not already under the psychosocial care of the primary investigator, was informed of this research study by a member of the psychosocial team during outpatient treatment visits. Recruitment continued until there were five research participants to fulfill the desired number of subjects for this pilot study. Given that this research project was a qualitative pilot study, the proposed sample size was considered reasonable to gain insight into the feasibility and acceptability of the intervention with this novel population. It was believed that this sample size would provide sufficient data to indicate if further investigation using Dignity Therapy in the BMT population was warranted.

Inclusion criteria included: 1) allogeneic blood or bone marrow stem cell transplant patients being treated for multiple myeloma, leukemia, or lymphoma, who were at least 60 days post-transplant, 2) expressed interest in Dignity Therapy, which was assessed by verbal consent, and felt motivated to take part in the study procedures, 3) English speaking, 4) a minimum of 18 years of age, and 5) able to commit to three in-person sessions at a large metropolitan medical center.

Research indicates that although recovery extends for arguably the rest of one's life following transplantation, general physical, emotional, social, and role functioning are similar to baseline for this population at about one year following transplant (Pidala, Anasetti, & Heather, 2009). We therefore wanted to capture the post-allo-BMT experience at a time that was in

proximity to having the greatest emotional toll; however, that was also far enough away from the transplantation where patients were not imminently confronting their possible death.

Participants

Demographic information is outlined in Table 2. Participants were two women and three men between the ages of 36 and 65 (mean = 54 years old). Participants were all married and Caucasian and had at least a high school education. Only one participant did not have children, and three did not have grandchildren. All were currently not working. The average number of days following stem cell transplant was 135.

<i>Table 2. Demographic Characteristics of Participants in DT Intervention</i>	
Total number of participants	5
Sex	
Male	3 (60%)
Female	2 (40%)
Married	5 (100%)
Caucasian	5 (100%)
Had children	4 (80%)
Had grandchildren	2 (40%)
12 [≤] years of education	5 (100%)
Age	Average = 54 years old (range 36 to 65)
Days since transplant	Average = 135 days (range 70 to 270)

Protocol

The psychosocial team, which consisted of one practicum student, two psychology postdocs, and two full-time psychologists, were informed of the study details and agreed to assist with the recruitment of research participants for this study. Interested patients received an information sheet (see Appendix B) with the contact information of the researcher provided. If

they preferred, they were also able to request to be contacted by the researcher by signing a HIPAA form and providing the psychosocial team member with their contact information. When participants were contacted about the study, more information about the research was provided using a script provided by Dr. Chochinov in his book and outlined in Appendix C (2012, p. 61).

Any questions or concerns were addressed with the potential participant. If the potential participant was interested in participating in this research project, and the eligibility requirements had been verified, the three research visits with the participant were scheduled with every effort made to arrange these meetings during a scheduled medical appointment.

At Visit One, which was about 30 minutes in duration, the consent form was reviewed, the participant had time to ask questions about the research protocol, and the informed consent document was signed if they were willing to participate. After consenting, the participant was given the demographic questionnaire to complete (see Appendix D) and was also given the list of ten Dignity Therapy questions in preparation for their next research visit (Appendix A).

At Visit Two the Dignity Therapy interview was conducted and audio recorded. This visit lasted approximately two hours. The interview was then transcribed in no more than three days by a research assistant and edited by the researcher in no more than two days.

At Visit Three, the edited transcription was read aloud to the participant and feedback/edits were solicited. The participant then completed the Participant Feedback Questionnaire Form (Appendix E) and was also asked for qualitative feedback about his/her experience. Feedback was written down by the researcher. This visit lasted about two hours. The final version of the interview was completed within no more than two days following Visit Three and was mailed to the participant following a discussion regarding the patient's interest in

sharing the document with his/her family. No data was collected concerning the sharing of the generativity document.

It should be noted that there were some slight modifications made to the standard DT intervention which was initially intended for use with hospice patients, in order to make the intervention particularly relevant to a non-imminently dying population. For example, we removed the second portion of question three from the interview which stated, “Are there particular things you would want [your family] to remember about you?” Modifications were made in collaboration with Dr. Chochinov during a telephone conversation with him in preparation for the implementation of this protocol.

Analysis

The quantitative data that is part of the follow up questionnaire was collected for the purpose of answering those questions and to help inform these researchers if the Dignity Therapy intervention could be used on a larger intervention trial with this population. Therefore, this data will not be subjected to formal quantitative statistical analyses particularly given the small number of participants in this study. Descriptive data will be presented in the results section.

In regard to the analysis of the qualitative data, however, the researchers employed a modified variation of the Consensual Qualitative Research (CQR) method to draw conclusions about the data collected. First I will highlight the central components of CQR, then I will elucidate the exact method utilized in this study, and finally I will cover the specific areas in which our analysis method compared and contrasted from standard CQR. According to Hill et al. (2005) the essential components of CQR include open-ended questions in a semi-structured data collection technique, allowing for the collection of consistent data across individuals, while also

obtaining more depth of examination on an individual experience. In addition, there are typically multiple people responsible for data analysis to introduce a variety of perspectives. Consensus of the data analysis is reached in an effort to make conclusive statements about the meaning of the data, and there is at least one auditor to assist with consensus judgments and verify the nature of the work being conducted by the research team. CQR adopts elements of phenomenological, grounded theory, and comprehensive process analysis, in an effort to arrive at a consensus among multiple judges thus working to avoid researcher bias and construct findings via narrative rather than numerical data. Furthermore, it is a tenant of CQR that researchers recognize that biases are a natural component of any research process and it is therefore encouraged that biases and expectations are honestly assessed and discussed (Hill et al., 2005).

Our process of data analysis began with the primary investigator reading about CQR and informing the research assistant of its principles. Interviews were transcribed and checked for accuracy, identifying information was removed and cases were assigned code numbers. The primary investigator worked to identify personal biases and expectations prior to analyzing the data, as this is standard practice when using the CQR method, which are reported within the Discussion section of this paper. The primary investigator and the research assistant independently read the de-identified narratives, first to become familiar with the content, and then again to begin the process of collecting themes. Each researcher listed all of the relevant topic areas, or domains, for each of the five narratives over two time points to ensure comprehensiveness, conciseness, and the utilization of the patient's own words as frequently as possible. The primary investigator then arranged these lists side-by-side for comparison and each researcher then independently created a third list for each narrative which was composed of only the agreed upon themes, or core ideas. These third lists were compared and cross-checked to

verify that none of the overlapping themes had been missed. At this point, the auditor received the two anonymous theme lists for each narrative and the compiled third list of overlapping themes for each narrative. The auditor addressed particular areas of analysis that she felt may have been influenced by subjectivity, and the two researchers, with this new perspective, revised their compiled lists accordingly. The team now had five individual lists of themes with which there was a consensus. These five lists were then compared independently for overlapping and/or related themes, which were compiled into a final list using terms agreed upon by the two researchers with hopes of capturing the essence of the group of narratives, and which again was supervised by the auditor. Once the analysis was complete, information regarding frequency was collected to indicate the degree to which each theme was represented across the sample.

In concordance with the CQR method, our study used the semi-structured interview outlined in Appendix A. We had two data analysts who comprised the primary set research team and each drew and collected relevant thematic topics within the transcribed narratives independent of one another. Consensus was reached among these two members of the research team, and auditing was conducted by the faculty advisor. Also in alignment with CQR considerations related to samples, research participants were selected from a homogeneous population who had awareness of the phenomenon under investigation. Although we would have preferred to adhere to the sample size guidelines indicated by Hill of about eight-15 participants, we felt that given the pilot nature of this study and that the sample size available was very homogenous, five participants was sufficient to assess interest and acceptability. Another important deviation from the standard CQR protocol is that discussions regarding themes and consensus were conducted entirely by phone and email, given that the primary investigator was out of state on her pre-doctoral internship throughout the analysis phase of this project. It is

unclear exactly how this may have influenced the consensus reaching process although it is hypothesized that richness and depth of dialogue among the research team may have been sacrificed.

Data Monitoring

The following information was collected during this research study; participant's name, phone number, and mailing address; demographic information (Appendix D); audio recordings of the Dignity Therapy interview and editing process; feedback questionnaire (Appendix E); and transcribed interviews.

Participant's name, phone number, mailing address, and demographic information were kept in a password-protected data base on a locked computer. The participants were assigned a code number which was also stored on this data base. At the completion of this research project, all information was deleted. The audio recordings were stored with the de-identified code number. These audio recordings were destroyed at the completion of the transcription and editing process. The feedback questionnaire and qualitative data were identified only by participant code number. This data was stored electronically in the locked data base mentioned above. The paper copies were shredded and the electronic data were deleted at the completion of this research study. The transcribed interviews were stored only as de-identified password protected copies on a locked computer. These files were deleted following the completion of this study.

Results

We begin the results by comparing the demographics of our sample with the general population of BMT patients to help readers place our sample in context. In terms of

demographics, according to the US Department of Health and Human Services, about 77.5% of those in need of a related and/or unrelated allogeneic bone marrow transplant are White, in comparison to 100% of our population. Also, according to the Leukemia and Lymphoma Society (2015), women comprise of 42.5% of all new Leukemia patients, 45.8% of all new Lymphoma patients, and 43.9% of new Myeloma patients.

I will now introduce each of the participants and give an individual overview of their Dignity Therapy experience. All patients gave written informed consent to include the use of anonymous sections of their interviews. To protect confidentiality, pseudonyms are used and some details have been changed, but every effort was made not to alter the meaning of their stories.

Case Studies

***Participant 1** Ms. (A) was a 38 year old married woman and was on medical leave from her job at the department of public health. Ms. A was diagnosed with acute myelogenous leukemia in 2013 and was day +92 from her stem cell transplant. Ms. A was a soft spoken woman who sat across from me at the interviewing table wearing a purple bandana that just allowed for the small wisps of hair that had started to grow back to show.*

Ms. A had lived carefully and had worked hard throughout her life, first as an artist, and then returning to school to pursue something “more meaningful” as a medical technician. Although Ms. A had grown up in a loving family, she remembered being bullied tremendously in school because of her shyness. She attributed much of her strength of character to her experiences being bullied as she felt that it facilitated a process of becoming more self-reliant and aware of the suffering of others. Ms. A described her life as lucky, accomplished, fortunate,

and fun. When she heard her diagnosis, after overcoming initial denial and then reflecting on her life, she felt somewhat prepared for the possibility of death given her sense of life fulfillment. She discussed with me how focusing on the positives, i.e. her young age and general level of fitness, while blocking out any potential negatives allowed her to fuel her strength throughout her cancer journey. Her mantra became “it’s curable and it’s doable” which her oncologists continued to assure her of as best they could. Ms. A talked at length about her family, most notably the support she received from her mother, who lived with Ms. A and her husband for months following the transplant. They appeared to have a longstanding positive relationship and her mother seemed to busy Ms. A with craft projects to keep her mind occupied during her recovery period. She also talked about the strain her cancer journey had placed on her relationship with her husband. She felt as though he took the diagnosis harder than she did or could and that he has, in ways, needed more care taking. Despite this, she continued to consider her partnership as a team and met these obstacles as “part of the evolution” of their relationship. Ms. A felt that she learned from her mother to live fully and love deeply, while from her husband she learned to be assertive and to trust herself. Ms. A described feeling alive throughout her life at moments when she felt free and adventurous such as when she first learned to drive or when she and her husband picked up and moved to a new city a few years ago. She felt proud of the way she handled herself throughout her cancer experience and talked about the outward signs of her illness such as losing her hair as a “badge of honor.” She wished for her family to take care of themselves, to do whatever made them happy, to relax every once in a while, and to remember how fortunate they are and have perspective when navigating difficulties. For herself, she hoped that she could find a way to manage her fear of recurrence and that she can work to strengthen her relationships following her healing process.

Participant 2 (Mr. B) was a 47 year old married man with children who was currently on leave from his job in the field of finance. Mr. B was diagnosed with acute myelogenous leukemia in 2013 and was day +105 from his stem cell transplant. It was immediately evident that Mr. B was a driven and positive man and that this, along with support from his family, bolstered his strength throughout his cancer process. He had a large smile across his face and wore a well-loved track suit. Mr. B had come prepared with written talking points and spoke with conviction about his experiences.

Mr. B was raised in a large family and remembered long summer nights in the Midwest playing outdoors with family and friends from his neighborhood when he was a little boy. He talked about attending college, meeting his wife while on an overseas exchange program, having his own family, applying himself fully in his work, and running marathons for exercise and pleasure. It was after experiencing a gradual slowing down of his ability to run that he visited the doctor and received his diagnosis. He described “knowing something wasn’t quite right” and then feeling as if he had “been thrown in jail without knowing what he did,” after hearing it was cancer. Mr. B’s initial treatments were unsuccessful and he talked about quickly realizing that he “couldn’t force this to go as he would like it to.” He worried constantly about his children and his wife and did not try to deny his thoughts about the possibility of death. But he also remained hopeful and described losing himself in thoughts about past family vacations or being at his parent’s lake house as a boy. Mr. B discussed finding pride in his ability to provide for his family and in teaching his children the value of hard work and of independence and patience. He couldn’t put his finger on a particular lesson learned from his cancer treatment, noting that he felt it was perhaps too soon to know how this will change his life outlook. He did, however, discuss feeling changed by experiencing the immensity of support shown by others and hoped that he

would be able to reciprocate for someone in need. He talked about staying present and appreciating the relationships and sacrifice of others, hoping his family could remain healthy, and wanting to become more involved with his children's lives post recovery. Mr. B discussed feeling as though he lost his sense of invincibility throughout the diagnosis and treatment process and gained a stronger sense of appreciation for what he has in his life. He talked about looking forward to going to a baseball game with friends and having a beer again. He hoped for his children that they would take risks and travel. And he talked about returning to a sense of normalcy as his most dearly held hope for his future.

***Participant 3** (Mr. C) was a 66 year old married man with children and grandchildren on medical leave from his job as a school teacher. Mr. C was diagnosed with chronic lymphocytic leukemia about eight years ago and was day +258 from his stem cell transplant. He was a tall gentleman dressed in a crisp suit and was carrying a brief case.*

Mr. C spoke about coming into his cancer experience with the gifts of previous good health and a "lucky" childhood. He spent much of his youth playing music and having involvement with local theater and knew from a young age that he had wanted to be a school teacher after having an incredibly influential teacher. He talked about stumbling into his first teaching experience having been "ill-prepared" but then learning to love it and going on to have a successful career. When Mr. C was first diagnosed with cancer, which was three weeks after marrying his wife, he described not being "tremendously affected" by it at the time. He went to regular treatment appointments and was able to carry on with his day-to-day life. It wasn't until 2012 that his illness became more serious and that he began the transplant process. He described feeling confident in the treatment, yet overwhelmed with the process of having to move to a new

city to receive it and uproot the life he and his wife had built. In fact, he talked about this process having been more stressful for his wife given that he had the “luxury of being sick” and thus having to focus on the one goal of getting better. Mr. C spoke about one moment in particular that has stayed with him throughout his treatment when the day after his transplant one of his oncologists said to him “well, it’s not like they tell you in the brochures is it.” He noted that he felt this point was very apt and that he is still coming to appreciate it fully as he continues the recovery process, which has been ridden with “ups and downs.” Mr. C spoke about not wanting to trust the “ups” despite feeling better in those moments and wanting to take on more in his life as there was a part of him that “knew a bomb could fall out at any minute” and he wanted to protect himself against false hope. Along these lines, he discussed losing a sense of certainty and the ability to plan for the future after being confronted with his mortality, as well as having lost his sense of health, financial security, and the strength of some relationships. At the same time, he has learned of the capacity of generosity in others, noting multiple occasions that he and his wife have been “overwhelmed with awe and gratitude towards people who have done nice things” for them. Mr. C discussed feeling alive when he felt purposeful with his students; when he has felt that he’s made an impact even on one child’s life. He also discussed feeling “guilty” for burdening his wife and hoping that they could return to their lives prior to transplant. Mr. C spoke about his thoughts of death throughout this process, noting that there were times that he was in so much pain and so physically limited that he thought to himself that it was a possibility that he might not survive. He talked about not wanting to die, but feeling as though he did not have any regrets in his life, despite having made some mistakes along the way. He talked about his role as a brother, a teacher, a partner, each as a separate and equally important thread throughout his life. Mr. C hoped that his family, his students, his step-daughters, that they would

each find their own way through life and not be afraid of making mistakes. And he hoped for himself that he could return to work and to his life and that he could remain patient throughout this process that he was sure would be ongoing.

***Participant 4** (Ms. D) was a 64 year old married woman with children and grandchildren who was currently on medical leave from her business in garment design. Ms. D was diagnosed with acute myeloid leukemia and was day +270 from her stem cell transplant. She spoke slowly and softly of her past experiences.*

Ms. D. began her interview describing a hard working yet incredibly loving family of origin. She talked about growing up on a ranch, trading less desirable chores with her brother, and learning to ride wild horses. Ms. D was raised with a strong sense of faith and still attended church regularly with her family. Later in life, she experienced a great deal of tragedy; marrying an abusive husband, losing their first baby in childbirth, and her daughter being diagnosed with cancer. Ms. D eventually divorced her husband and raised her two children on her own, remarrying when her children were graduated from high school. She described herself as a “master of lists” always keeping her children to a tight schedule and working multiple jobs to make ends meet. After years of working in odd jobs and with the support of her family, Ms. D started her own garment design business, which gave her an enormous sense of pride and accomplishment. Ms. D talked about how close she and her children became and how they have each filled a role in her caretaking since she became sick. Someone helped with making meals, with the finances, with setting up fundraisers, with researching medicines, etc. She described the diagnosis as being difficult for everyone in the family, particularly her husband, as he has felt that he has had no control and has had to help Ms. D fight from the sidelines. Ms. D talked about

believing in miracles and how she had hung a sign in her hospital room that said “believe even when there is no reason to believe.” She discussed having always been able to “conquer” whatever has come her way and how this cancer process has only left her prone to “trust more in God.” Ms. D spoke about the importance of “family love” and about how grateful she was for her cousin, who was her stem cell donor, and whom she described as “giving her a second chance at life.” She hoped for her family that they will have the faith that she grew up with and that she considers to be a central component of her battle with cancer thus far. She also hoped that her children and grandchildren would have strong determination and not let others negatively influence them. At the worst of times, Ms. D talked about feeling “helpless” and focusing only on the losses she has experienced and how dependent she has had to be on others throughout her treatment. She also spoke earnestly of being in awe of the support her family and community has given her, and hoped that, should this journey come to an end, that she would be remembered for being a “strong and loving person.”

Participant 5 (Mr. E) was a 61 year old married man with children and grandchildren on medical leave from his job at a tech company. Mr. E was diagnosed with myelofibrosis in 1991 and was day +70 from his stem cell transplant. Mr. E spoke with a cautious tone and started off thanking me for the opportunity to discuss his journey.

Mr. E began by explaining that he had no regrets in his life and that although he had experienced a great deal of adversity, he did not consider his life to be anything extraordinary. He talked about having a strong sense of caring for his family and how they have been the central motivating factor in his treatment. Mr. E spoke of a history of working towards self-improvement and subsequently embarking on the process of self-discovery starting years before

his cancer diagnosis, which he felt had prepared him in ways for the difficult process of stem cell transplant. He described his family as his “anchors” throughout this process and considered his roles in their lives as his largest source of pride. Mr. E talked about the stability in his relationship with his wife, who was his primary caregiver, and how he could not have survived the treatment if it wasn’t for her support. He spoke about experiencing a great deal of pain and physical weakness, but trying to focus on how fortunate he is to be alive. Mr. E was raised to value stoicism and self-reliance and because of this, he had not spoken about his cancer experience in depth with anyone in his family. He spoke of the strength and “mental toughness” of his mother and how his sense of perseverance, passed down through her, has helped him manage his cancer. He hoped for other cancer patients that they not to grasp too tightly to positives as to be disappointed when the inevitable negatives present themselves, to “live in the present,” even if that is “day by day or hour by hour,” and to know that even though things may feel grim, that “it’s not forever” and to remember the reasons you are trying to extend and improve your life. When Mr. E experienced loss of hope during his treatment, he remembered his commitment to the treatment and his appreciation for everyone who was helping him. He described his biggest fear as burdening his wife with the logistics of caregiving and as his family not knowing how much he cares for them.

Qualitative Analysis

Four domains, or overarching themes, emerged from the data: pre-cancer life, the diagnosis and treatment experience, the post-treatment experience, and sources of support and pride. The domains, categories, and frequencies of each of these can be found in Table 3. In the table, all thematic findings are listed to provide the range of topics that participants discussed. In

reality, these thematic findings could likely have been organized into a variety of different domains; however, we felt that by categorizing the data in this manner, we could better understand the impact of the cancer journey on the patient, which would also help us better conceptualize the utility and meaning of the DT intervention on this population.

Table 3. Domains, Categories, and Frequencies for Thematic Findings

1.	Pre-cancer life	
	Happy, well supported family upbringing	4
	Having no prior knowledge of cancer and not being <i>fully</i> prepared for BMT	4
	Having always had the capability of fighting illness before cancer	2
2.	Diagnosis and treatment experience	
	Struggling with fears and thoughts of death	5
	Importance of staying present and positive throughout treatment	4
	Importance of trusting the treatment program	4
	Suddenness of learning one's diagnosis	4
	Continuing to be able to provide for family/feel productive as source of pride	4
	Life being turned upside down with diagnosis	4
	Treatment being a "rollercoaster" as many treatments did not go as planned	4
	Cancer disrupting career path	4
	Diagnosis being harder on partner	3
	Spent time alone reflecting, meditating, and recalling positive memories	3
	Relied on inner strength and self confidence	3
	Kept an online blog	3
	Denial as initial response	2
	Focused on what was "doable" during treatment	2
	Difficulty sharing diagnosis with social network, tended to self-isolate	2
	Complications in treatment led to increased difficulty coping and death thoughts	2
	Hoped for a miracle throughout treatment	2
	Was sick for so long, had gotten used to feeling sick	2
	Importance of being able to deprioritize everything but recovery	2
	Felt burdensome to family	2
	Found self researching online following diagnosis	2
3.	Post-cancer treatment experience	
	Having to cope with fear of cancer recurrence	5
	Being filled with gratitude and motivation to give back to cancer community	5
	Anxiousness and eagerness to return to normalcy	5
	Cancer experience increased awareness of others' struggles	4
	Looking forward to taking a trip on a plane again	4
	Cancer experience having strengthened individual relationships	4

	Loss of invincibility (financial and physical)	3
	Feeling fortunate to be alive	3
	Upon reflection, life seems like preparation for dealing with cancer	3
	Wanting to have an alcoholic drink again	2
4.	Sources of support and pride	
	Centrality of having a loving and supportive family	5
	Being in awe by response of friends and generosity of others	5
	Wanting family to know how much the patient cares for them	5
	Importance of leaving a legacy to family	4
	Having pride in academic and professional accomplishments and relationships	4
	Having no regrets in life	2

Note. Frequencies are noted as number of times theme is represented among the narratives.

In text, I will discuss only the thematic findings that were represented across all five narratives which were; struggling with fears and thoughts of death during the treatment process, having to cope with fear of cancer recurrence, centrality of having a loving and supportive family, wanting family to know how much the patient cares about them, being in awe by response of friends and generosity of others, being filled with gratitude and motivation to give back to cancer community following treatment, and anxiousness and eagerness to return to normalcy.

Struggling with fears and thoughts of death during the treatment process

Participants discussed entertaining thoughts of death in a variety of ways throughout their treatment. Some discussed thoughts of death as more of a vague, distant concept that felt unfamiliar and foreboding, while others who had experienced many forms of loss prior to their diagnosis, including having family histories of cancer, greeted their fears and death thoughts with fluency. Regardless of their individual reactions to thoughts of death, each discussed the inevitability of these thoughts as a cancer patient and factors that exacerbated or mitigated them.

For example, one participant noted that when these thoughts arose, they would often consider how fulfilled and lucky they felt to live the life they had lived prior to their diagnosis. They described trying to maintain perspective on their own suffering in comparison to the suffering of those even less fortunate than them and how necessary it was to ponder these thoughts as they will inexorably arise. One participant said,

...yeah I could die. I guess I could die during this thing and what a horrible thing to have to think about. I mean everybody dies so that was one of my things and I try to spin it and say I've been pretty lucky, I've had xx wonderful years. I mean I have really no complaints, I've never starved, I've never been abused or anything. I've just had a wonderful life and there are people who don't even make it to their first birthday. So, that's kind of depressing thoughts, but you can't help them, you have to process them in your head and everything. And that did give me some comfort to know that, I mean that I have had a great life, so far. I'd like to continue it for as long as possible, but I have no complaints and I know that everybody has a time, I just don't want it to be too painful or if I can make a request, you know. That entered my head a few times and after the denial phase you kind of then start thinking the worst part of everything.

Other participants discussed the intricate relationship between the treatment successes and failures and their thoughts of death. One person explored how they were overtaken with fears and worsening thoughts of treatment failure when they experienced pain or contracted an infection. The participant noted,

I think when I had that infection, your mind is racing when you have those high fevers, you can't even control your thoughts and I remember thinking that this infection is going rage through my body and they're going to have to cut off an arm or something. It was stuff I couldn't even stop my mind from thinking about because it was almost like I was hallucinating. So that was probably the time when I had really scary thoughts kind of crept into my head.

Having to cope with fear of cancer recurrence

Each participant expressed a hope for themselves that they could learn to live their post-treatment life in spite of the everlasting fear of cancer recurrence. These fears were not limited to blood or bone marrow cancers, but also included the fear of secondary cancers rooted in the carcinogenic effects of the cancer treatments they had undergone, and also included fears for their loved ones being diagnosed. Not one of the participants discussed an expectation that this fear would ever dissipate; however, instead, they articulated a desire to coexist with the fear of recurrence. For some, these fears began as early as during the treatment process, prior to having survived the blood or marrow transplant, and even at times trumping thoughts of death. For example, one participant stated,

During the time I was in the hospital, my bigger worry was what if this cancer comes back or what if the stem-cell transplant doesn't work or kind of all these short-term things, what if they can't find a donor? Like, what if we found a donor but there were

some things that caused some delays and we thought this whole thing was going to fall apart and we are going to have to go back to square one and find a new donor. That's going to take another month, and in the meantime this cancer might start coming back.

Other participants discussed their anticipation for feeling a balance between acknowledging the presence of recurrence fears but not becoming overpowered or paralyzed by them. Participants mentioned their expectation that these fears may preclude them from feeling as they did prior to the cancer diagnosis, despite being cancer-free, and also the hope that with the continued passing of time without recurrence, that these fears may loosen their grip on the participant. For example, one participant said,

I hope I can figure out how to coexist with this dark cloud in the back of my head. I'm not sure yet how to do that totally other than just kind of ignoring it, but I don't think that's the healthiest way to deal with reality. I think it's just something that's going to take a while and maybe as time goes on it will get a little bit better. Just to keep coping with it even though there is a slight possibility that something can happen again.

Centrality of having a loving supportive family

Participants discussed the centrality of having the support and love from their families both prior and during their cancer journey. They all expressed immense appreciation and fortune for having these relationships as well as the acknowledgement that this was in fact a critical

component of their survival given how much the participant had to rely on their presence and support. One participant stated,

Its life altering, it reminds you how vulnerable you are and that you sure can't make it alone. And you better not take anybody for granted that's helping you. And you better give back to them.

Again, participants shared how valuable and influential their family upbringings were in preparation for handling their cancer journeys. Another participant said,

I think my biggest hope and prayer is that they will also have the faith that I grew up with, and I guess confidence, setting your goals and going toward them, and love. That is so important. I grew up in a close family and now that my kids are married and so forth, we are together a lot. I've appreciated so much from my family.

Wanting family to know how much the patient cares about them

When asked what the participants would like to pass on or share with their families, every participant replied that they wanted to make sure their loved ones knew how meaningful they were and how appreciative the participant was towards them. There was a resounding message of wanting families to know how much the participant cared about them. Some felt as though they had been open with their loved ones about this in the past and therefore used this as an opportunity to reiterate this important message. For example, one participant said,

I'd do anything for any of them. There's nothing that I really have to inform them of about me. But I want to make sure that they know that I care about each of them very deeply.

Participants also used this experience as an opportunity to share their hopes that their love and care for their families will outlive them and continue to influence those they love, as their parents and grandparents did before them. They discussed recognizing that much of their strength stemmed from the love they felt from those who came before them and hoped that they would instill this support in those they may leave behind. One participant said,

I guess one of my biggest wishes in my life has always been that my children and my grandchildren will- I don't know how you would say it- but my mom, she was a very hard worker, she wasn't beautiful or anything like that, she had rough hands and no fingernail polish and so forth, but you could tell she had all the love in the world, and the grandchildren just worshipped her, my brother and I did too. My dad too, but my mom, just the honor. And I've always hoped that I would have that same influence on my children and grandchildren. And in some ways I think I have, my one nephew always calls me the rock. But I just hope that I make a good mark and that people remember me as a strong, loving person and that's just my main wish that they'll understand how much I've loved them and cared about them.

All participants discussed experiencing an outpouring of support by their community, whether it be in the form of bringing over food or helping with running errands, people coming out of the woodwork of one's past or one's neighborhood upon learning of the participant's diagnosis with financial or emotional support, or simply just keeping the patient company. Furthermore, each participant expressed amazement at the generosity of others as the support they received far exceeded what they could have possibly expected. This seemed to have a profound impact on the participant's ability to remain healthy, focused, and positive throughout their recovery process as they were continuously being cheered on by their community at large. One participant expressed their shock of learning that people had donated money to helping to cover treatment costs. They said,

Well, the thing that has struck me the absolute most that I have learned is how generous people can be. My partner and I have had many instances over the past year and a half in which we were totally, and I mean totally, overwhelmed with awe and gratitude towards people who have done nice things for us. I mean, I can think of two examples that occurred absolutely out of the blue, where we didn't expect them in anyway and didn't have any reason to be expecting them. People donated money to us that was above and beyond what we would ever expect, just because they wanted to do it.

Another participant discussed realizing that they had a larger supportive network of people in their life than she had been aware of prior to her cancer experience. They also talked

about being surprised at this response by others as they had never considered themselves to be extroverted or particularly social. The participant said,

...you never realize how many friends you actually have. Even now, yesterday I got three cards and I have been getting cards continuously from friends and calls and visits, it's overwhelming. That part has just been overwhelming because there's people that yeah I knew them kind of, but I never really, you know they're what I would call a different society. And here she came into the hospital to visit me and she's been sending me cards all the time, and others. It's just been totally amazing.

Being filled with gratitude and motivation to give back to cancer community following treatment

Every participant described a desire to give back in some way to the cancer community once they had achieved health. Participants discussed that along with the doctor's appointments and hospital stays and difficult treatment processes came membership to the cancer community, which is comprised of survivors, volunteers, families and loved ones of patients, their medical teams, counselors, and other cancer patients. Many felt that this community was critical to their own survivorship and also many felt that this was not something that they wanted to lose now that they were not critically ill. Participants discussed feelings of gratitude and gratefulness which they wanted to re-gift in the early aftermath of their cancer treatment. One participant noted,

I'm going to do something that helps me kind of give back to the universe what I was given. I've already had one meeting this week that was with the volunteer program at the hospital where we live, where they're starting up a new volunteer program for cancer patients. I guess I'm one of their first volunteers, it's a brand new program.

Participants also discussed the profound importance of giving back as a mechanism of feeling purposeful and fulfilled in one's life following cancer and the many losses that are experienced despite surviving a stem cell transplant. For example, one participant said,

I definitely want to get more involved with volunteering. It just feels really good to do that, so I'm thinking about doing something either their volunteer program here or The Craic Addicts. It's a local group that they try to get people on the donor registry. Craic is like Gaelic for laughter or something like that. So something like that or Love, Hope, Strength, something like that. And then I just love Project Cure, so to continue with that and maybe a homeless shelter eventually. I just want to fill my time since we're not going to have kids, I think I need to fill my time with doing something productive.

Anxiousness and eagerness to return to normalcy

Finally, participants generally discussed a strong sense of wanting their lives to settle down following the long period of stress and upheaval that cancer had caused. Participants talked about their hopes for resuming their life routine including having a schedule filled with work and driving to soccer practice, instead of having to be housebound with fears of catching an infection

that their immune systems could not handle. Across all participants, there was discussion of both wanting to feel normal again, and also an awareness that “normal” may be a fabrication or may take hard work to achieve again. As one participant described,

It would look boring to anybody else. But I enjoy the role of support in the background, with my partner while they're still working, so I take care of the house, take care of the dog, take care of all the business stuff. I want to resume my golf. I'm going to have to rebuild that because my body has changed so much in the last year, so I'm going to have to take a while to get some strength back so that I can do that again. I have a good friend that I golf with and I want to resume that. I lived a very simple life.

As mentioned here, many participants noted that their wishes and desires for themselves following their cancer experience may sound “boring” to others, but that after having navigated their cancer and having been confronted with the possibility of losing everything, maintaining normalcy, despite sounding mundane, would actually be profoundly impactful to the patient as if they were looking at what was once normal with a whole new perspective. One participant said,

For me, kind of less change at this point is good. I'm anxious to get back to work, to get back into that routine. I have no intention of saying I need to do something else with my life starting tomorrow, that would just be too much, not that I even have anything in mind... Some people look at family suburbia life as boring but we like it. Yeah I think that's a good way to put it, getting back to the way it used to be... Yeah just going to a

football game or a baseball game, enjoying times with friends and family, and just sitting outside.

Patient Feedback

The patient feedback questionnaire utilized in this research project was provided by Dr. Harvey Max Chochinov. The questionnaire uses a five-point Likert scale where one signifies “Strongly Disagree” and five signifies “Strongly Agree.” A summary of the feedback data is presented in Table 4.

<i>Table 4.</i> Participant Feedback Questionnaire Data			
Item	Mean	Range	Comments
1. I have found the Dignity Therapy to be helpful to me.	4	3 to 5	<p>“It puts your thoughts in a different perspective when they are typed out and read by someone else.”</p> <p>“It helped form a lot of different thoughts and feelings into a coherent story.”</p> <p>“Listening to the transcription was very affirming for me.”</p>

			<p>“I am not sure what I expected but it seemed to be just telling my story.”</p>
2. I have found the Dignity Therapy to be satisfactory.	4.2	4 to 5	<p>“It seems like a very logical approach.”</p>
3. The Dignity Therapy made me feel that my life currently is more meaningful.	3.6	3 to 5	<p>“Hearing my story made it sound important.”</p> <p>“I think the whole cancer experience has made me feel that my life is more meaningful, not just D.T.”</p> <p>“The process of constructing my responses and hearing them read has an oddly reaffirming effect on how one thinks about their life.”</p> <p>“Not really. I always value my life so do not feel life has lost its meaning.”</p>

4. The Dignity Therapy has given me a heightened sense of purpose.	3.4	3 to 4	“Oddly, yes. It’s not a reaction I expected but it does make me feel a sense of fulfillment, awareness, and completion.”
5. The Dignity Therapy has given me a heightened sense of dignity.	3.4	3 to 4	“To hear my story made me feel like I am important.” “It makes me feel like my story matters.”
6. The Dignity Therapy has lessened my sense of suffering.	3.2	3 to 4	“It made my journey sound worthwhile.” “Possibly. This will take some time to know.”
7. The Dignity Therapy has increased my will to live.	3.2	2 to 4	“I was inspired by my own journey when it was read by someone else.”

			<p>“Again, possibly. It strikes me that this is one section of a puzzle to help patients in this regard.”</p> <p>“I never lost my will to live.”</p>
8. I believe the Dignity Therapy has or will be of help to my family.	3.4	3 to 4	<p>“I haven’t decided if I will share it with my family yet.”</p> <p>“I feel that reading my story would help people really know me.”</p>
9. I believe my participation in the Dignity Therapy could change the way my family sees or appreciates me.	3.6	2 to 5	<p>“After reading my story, they may see some thoughts that I have never verbally expressed in this way.”</p> <p>“No I don’t think it makes a difference.”</p>
10. I believe my participation in the	3	2 to 4	<p>“No clue. Some would definitely know more about me.”</p>

Dignity Therapy could change the way my health care providers see or appreciate me.			
11. In general, I have been satisfied with my psychosocial care.	4.2	4 to 5	<p>“I have been impressed with the care at XXXX, especially the holistic approach and the emphasis on psychosocial care and the availability of mental health services.”</p> <p>“This is a wonderfully valuable branch of our treatment. “</p>

In general, the participants found the intervention to be helpful to them (Mean=4, range 3-5), satisfactory (Mean=4.2, range 4-5), to make them feel that their current lives are more meaningful (Mean=3.6, range 3-5), to give them a heightened sense of purpose (Mean=3.4, range 3-4), to give them a heightened sense of dignity (Mean=3.4, range 3-4), to lessen their sense of suffering (Mean=3.2, range 3-4), to increase their will to live (Mean=3.2, range 2-4), to be of help to their families (Mean=3.4, range 3-4), and to potentially change the way their

families see or appreciate them (Mean=3.6, range 2-5). In addition, participants were generally satisfied with their overall psychosocial care at the medical center (Mean=4.2, range 4-5).

Patients neither agreed nor disagreed that their involvement in the Dignity Therapy intervention would potentially change the way their health care providers see or appreciate them (Mean=3, range 2-4).

Although it may be imprudent to devote much consideration to these data given the small sample size, there is a clear trend evident in this participant feedback indicating that the impact of the DT intervention was generally positive. Each of the mean scores fell within the upper portion of the numerical Likert scale indicating that the participants at minimum neither agreed nor disagreed with, but often times strongly agreed with each statement. The lowest scoring (Mean=3) component of the feedback questionnaire was related to the question regarding DT having an impact on the way the participant's medical team saw or understood the participant. One hypothesis about this relatively lower score may be due to the fact that participants were already very pleased with their care at this medical center, as indicated by question 11 which had one of the highest mean scores and asked about the level of general satisfaction with their psychosocial care (Mean=4.2). The other question showing the highest mean was question two which asked if the participant considered the DT intervention to be satisfactory (Mean=4.2). The remaining means fell within the three to four range on the Likert scale.

Furthermore, the additional comments participants left may be of value in better understanding the impact of this intervention on the BMT population. I will briefly present here a synthesis of these comments for questions where there were at least two comments made. For the first question, which was related to the perceived helpfulness of the intervention, most

participants commented on the DT process broadening their perspectives on and serving to integrate their own life-stories, which appeared to be a validating experience. For the third question, which was related to the impact of DT on life's meaningfulness, participants felt that hearing their story helped them feel important and that experiencing cancer in general had made their lives feel more meaningful. One participant commented that their lives had not lost any meaning. Comments for question five, which highlighted DT's impact on sense of perceived dignity, suggested that some participants felt a sense of self-efficacy rooted in their participation in this intervention. Participants commented on feeling that their cancer experience was "worthwhile" in response to question six, which inquired about reduced suffering. One participant also noted that they were not certain if DT had impacted their sense of suffering. In regard to question seven, which asked about the impact of DT on the participant's will to live, one participant commented on feeling inspired by hearing their own story read aloud by someone else, one noted that they were not sure of any relationship existing between their involvement and will to live, and one stated that they had never lost their will to live. Participants commented on either being uncertain of whether they would share their generativity documents with their families or feeling as though this intervention would increase understanding among their family members for question eight. For question nine, which was related to the potential impact of DT on the family's perception of the participant, comments indicated that there may be no potential impact, while some thought it would provide an opportunity for the family to learn more about the participant. Finally, participants commented on their resounding positive regard for their psychosocial treatment at this medical facility.

The final component of this research protocol was to ask the participant for any additional feedback that had perhaps not been communicated already. This was done in form of

providing a section for additional comments on the written participant evaluation form and was also done verbally following the completion of the evaluation. These verbal responses were recorded by the researcher.

In general, participants appeared to reiterate that they found the DT process to have been helpful for them and that they found the act of hearing their story to be poignant and touching. For example, one participant commented that he would, “like for this to be read at [his] funeral,” while another said that, “it was moving to hear [her] story read aloud.” Other participants responded by noting that they were overcome with feelings and even in shock at hearing their own words. For example, one participant exclaimed, “I’m not boring!” and another wondered aloud, “wow, are those my words?” and finally another participant said, “I’d need some time to process all that.” Lastly, participants seemed to reflect on the utility of the intervention and provided suggestions for future use. For example, participants said, “it was a great way to look a bit deeper into your thoughts,” “I appreciate being given the opportunity to participate,” and “Maybe starting it earlier during the leukemia and do a little at a time over the months.”

Discussion

Overview

To conclude this research paper, I will start at the beginning and first spend time discussing my biases, assumptions, and then my reactions and lessons gleaned from engaging in this project. I will then relate the results from this study to previous research on DT, discuss

some relevant strengths and limitations of this intervention, and highlight areas of potential future research.

In the spirit of CQR, it is critical to explore one's potential blind spots, assumptions, and expectations (Hill, 2005). Prior to starting this research project, I had been working with this patient population for about one year and found it to truly be one of the most uniquely beautiful groups of people with whom I had worked. Given the psychosocial circumstances faced by BMT patients, notably, the suddenness of diagnosis and the severity of the treatment, the BMT patient population is one that, in my experience, was very receptive to psychotherapeutic exploration and personal reflection. This created a rich opportunity for implementing the DT intervention, which I not only hoped would be helpful, but I undoubtedly expected it to be as well. These patients also had a great deal of time that was spent in isolation which again in my experience, was often spent thinking and ruminating, and so I had assumed that they would be well suited for such a reflective intervention. In addition, the more I read in regard to previous literature on the intervention, the more I felt that there were more similarities than differences among the non-imminently dying BMT patient population and other DT research populations. Yes, Dignity Therapy was originally intended to relieve existential distress in the very near end-of-life for both patients and families (i.e. Chochinov's book subtitle, *Final Words for Final Days*); however, end-of-life may not be the only context where end-of-life distress becomes relevant. Many of the patients with whom I had worked shared with me that they had been confronted with thoughts of death at some point between diagnosis, treatment, and survivorship. I couldn't help but feel that these thoughts, although not realized, had an impact on the patient's outlook. Furthermore, as discussed earlier, research with a non-imminently dying elderly population had proven the utility of DT even when death was not directly approaching, so I therefore expected

there to be similar relevance and usefulness in this population. Finally, I think there is a tendency for those of us who engage in end-of-life related care or general psychosocial oncology to have a desire to attend to pre-existing relational conflicts, personal regrets, or other sources of emotional pain with the hopes of reaching a resolution for our patients. We may think that now that someone has faced this enormous life threatening illness, a new perspective is gained where personal grudges or old conflicts become instantly put to rest. Perhaps we hope that we would be able to let go of our own hang-ups and be healed if we were to be confronted with something as meaningful as our mortality. Or perhaps it is just what we hope for our patients, or our personal preferences for families to be united and happy and safe when we know how trying a cancer journey can be. Whatever the reason, I am certain that I was expecting these research participants to not speak of family conflict or disappointments during their DT interviews, despite knowing that these dynamics are real and universal across all human beings, even in cancer patients.

I am very pleased to say that it appears within this small sample of participants that the DT intervention was indeed useful, helpful, and relevant. Participants were engaged throughout the process and reported both verbally and via the solicited feedback that they were grateful to have had this opportunity and felt it to be of benefit to them. At no point did any of the participants question their involvement in this research or ask to cease participation. It is not entirely clear given the lack of opportunity for follow up, but there were a number of responses on the feedback questionnaire that may have indicated a shift in relevance for this unique population. These included responses to questions about loss of will to live, changes in life's meaning, and reduction in suffering. I think it may be important to entertain the significance of these questions for a population that is on a path to survivorship instead of end-of-life. To my surprise, many participants did speak in one way or another about themes related to either family

conflict or personal shortcomings. There did not seem to be an overarching domain to capture this sentiment, however, I recall noticing my reaction to hearing one patient share about their disappointment in their brother's life choices, and another share about their self-loathing for having struggled with alcohol in the past. These feelings were raw and they were not pretty. But they were very real and they were very much a part of these people's cancer experiences and the meaning they had made of their lives. In the end, I was so appreciative that these participants weren't glossing over the tougher stuff and were allowing me to see just how truly complex and layered this time in their lives was. It served as a stark and important reminder that resolution to conflict may not be possible for our patients and also may not be their goal.

Linking to Previous Literature

This present research was unique in that it piloted using the Dignity Therapy intervention on a non-imminently dying, allo-BMT patient population, an entirely novel population for this intervention. It was not unique in that it suggests that the process of engaging in DT may be helpful in reducing existential and emotional distress, alleviating insults to dignity, and being a viable tool for facilitating understanding of the patient among families and medical teams. Similarly to a more imminently dying oncology or elderly patient population, the allo-BMT patient population experiences a fractured sense of dignity throughout their diagnosis and treatment phases, as well as in their survivorship phase, where patients are struggling to return to normalcy and integrate this cancer experience in a meaningful way. Referring back to the Model of Dignity in the Terminally Ill (Chochinov, 2012), all three dignity contributing factors are unequivocally affected throughout the blood and bone marrow cancer journey. Levels of independence are tested, physical and emotional symptom distress are prominent, social and

relational concerns including needing support while not wanting to burden others and losing a sense of privacy and boundaries are rampant, and patients often have difficulty engaging in dignity conserving practices and perspectives.

In addition, there were many similar qualitative results noted in these research results that overlap with the content provided in the work of Hack, et al. (2010). These researchers noted the most frequently spoken about themes in the DT interviews they surveyed included family, enjoyable activities, caring for others, sense of accomplishment, friendships, and richness of life's experiences. Referring back to Table 3, many of these sentiments are represented among our data as well. One important distinction in the qualitative results is that our participants spent a great deal of their DT interviews discussing details of their cancer diagnosis and treatment, hence why we felt it was important to separate the core ideas by domains chronologically, or in other words, by phase of treatment. It is hypothesized that perhaps these issues were more relevant to these participants because many of them were still in a either active treatment (less than 100 days since transplant) or in early survivorship, which may make diagnosis and treatment more salient as opposed to an imminently dying patient population who may have their attentions turned to other important sentiments. Further investigation into the discrepancies between content in the dying and non-dying cancer patient populations may prove to be quite helpful in understanding important distinctive and overlapping characteristics of these experiences.

Strengths of DT and This Study

The strengths of the DT intervention are manifold, particularly for vulnerable populations and when time sensitivity is significant. As mentioned, the duration of the implementation of the

DT protocol is intended to be quite brief, and can be shortened even further if necessary by turning around the transcription process more quickly. This may be necessary if the end of life is more imminent and time is of the essence. For the population under assessment in this study, which was a relatively healthy outpatient population, the proximity of the research visits were largely dependent on the availability of the participant and were on average within the delineated time frame. In addition, if needed, this intervention can be administered in a variety of different settings, including bedside, in the home, or as in this case, in an outpatient consultation room. In fact, a study conducted in 2004 suggested that the effects of DT conducted over videophone were comparable to in-person delivery (Passick et al., 2004). Another benefit of utilizing DT is the supportive and ameliorating benefits to the patient's caregivers, which is an unintended byproduct of similar interventions, although this was not directly assessed in the current study. Finally, DT has a presence in both a research and clinical capacity in many countries across the globe where it has been shown to be culturally conscious and both easily and meaningfully implemented (Chochinov, 2012). In regard to this research, this was the first time that this intervention was implemented with this population, and all participants completed the intervention and follow up portions of the protocol in full.

Limitations of DT and This Study

Although DT has been shown repeatedly to have a therapeutic effect and to do so at minimal risk to patients and families, there are some important limitations to be aware of. As of now, research continues to be limited in understanding the potential impact of DT on patients with marked psychological pathology or among particularly high-conflict families. One might imagine that a patient's experience of participating in this type of intervention may be heavily

influenced by psychological wellbeing and it is not yet understood how DT may be of help to patients beyond the cohort of “normal” functional capacity. In addition, the impact of reading a family member’s generativity document whom one may have experienced as abusive or unavailable within the family context is also unknown. It is important for us as clinicians to appreciate that the patients and families we work with existed long before their cancer diagnoses and most certainly are engaged in family dynamics that may affect their receptiveness to the DT intervention. Along those same lines, the DT intervention and the creation of a permanent, written generativity document allows for the opportunity for discrepant recollections to be recorded, which some family members may experience as invalidating. This is the rationale behind excluding patients with cognitive deficits from engaging in DT. Finally, a common criticism of DT is also one of the strengths mentioned above: that the intervention is quite short from beginning to completion. Although this may be helpful in certain circumstances, many patients benefit from more ongoing clinician contact and may feel prematurely abandoned after engaging in such a brief intervention.

Future Research

Most notably, this research is limited by the small sample size and the subsequent narrowness of the conclusions that can be drawn. The purpose of this research was to begin to assess the feasibility and practicality of implementing DT, which although we can conclude from this study that DT appears to be feasible, practical, and meaningful, the small sample size precludes us from fully understanding the impact of DT, as it is quite unlikely that five research participants are representative of the diverse and complex BMT patient population. In addition, this study did not assess beyond the immediate post-intervention impact of DT on the patient

population. Pre-assessment, long-term follow up, and the effect of the intervention on the caregiver were all not assessed.

Although we did not collect information about the patient's psychosocial distress at baseline, it can be concluded that the DT intervention did, on the whole, have a positive effect on the participants' psychosocial wellbeing given the trend indicated on the feedback questionnaires. It would be quite worthwhile for future research to compare measures of psychosocial distress, quality of life, and perception of dignity at baseline and after implementation for this patient population. In previous research, dignity related distress was measured using the Patient Dignity Inventory, a 25-item measure developed from the dignity model outlined in this paper (Chochinov, 2012). In addition, given that risk of psychiatric episodes in cancer patients is increased by past psychiatric history, and that the patient's pre-transplantation psychiatric status is predictive of functioning following BMT, it may be beneficial to implement the DT intervention prior to transplantation as a preventative measure against further worsening of psychosocial distress (Hall, Goddard, Speck, Martin, & Higginson, 2013). Future research may also wish to assess the impact of the DT intervention and reading the generativity document on the BMT caregiving team. Particular concerns about misrepresentation or discrepancies in memories of certain events and the manner in which the document is managed and stored may be of unique relevance, as well as the level of willingness to share the document with loved ones during or after survivorship. Again, the present research reported on a very small sample size. Future research would first and foremost greatly benefit from increasing the size of the research population and conducting larger-scale quantitative studies. In addition, it would be of particular interest to this population to investigate the factors that may exacerbate or mitigate dignity related insults (for example, length of hospital stay, relationship with medical

staff, etc.), and by using other known predictors of poor post-BMT quality of life (for example, greater degree of symptoms, lower education level, older age, female sex, sexual impotence, advanced disease at time of transplantation, presence of chronic GVHD, worse pre-transplantation level of functioning and impairment, greater interpersonal conflict, and reduced level of social support) to better address the questions of who this intervention may be relevant for (Pidala, Anasetti, & Heather, 2009).

Closing Remarks

We have now come to the end. So far, we have looked at the early underpinnings of dignity research with its roots in Dutch physician-assisted suicide data, overviewed the Model of Dignity in the Terminally Ill, delved into previous research supporting the utility of DT in various patient populations, and explored this current research. We have met five brave cancer patients who have generously and humbly shared their stories in the pursuit of research, but who hopefully also gained something from this experience as well. I know that I have learned much from my involvement in this research and I am so thankful to have been able to work with these patients and research team members and to have had the opportunity to reflect on my own journey as an early psychosocial oncology provider. It is imperative that we value the consequences of shattered dignity and listen for its evidence. Every person has a story to tell and having that story heard and valued can be a powerfully validating, if not inherently dignifying experience in and of itself. Just because we survive a life threatening experience, does not mean that we feel cured or strong, or that we've reached some transcendent perspective on our life's pains, or that we don't continue to live in the shadow of being confronted with mortality again. People are so resilient, but we often don't face challenges entirely on our own, and for that, there

is enormous gratitude and appreciation. And when we do survive, we are often compelled to give something back and to lessen the strife of others. Finally, in the aftermath of cancer, people seek normalcy, routine, and calmness. Perhaps appreciating these simplicities is a lesson from which we can all benefit.

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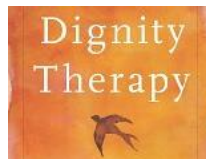
Dignity Therapy Question Protocol

Please take some time to reflect on the following questions prior to your scheduled Dignity Therapy appointment. This protocol will form the structural basis of your Dignity Therapy; however, if there are areas or issues that you wish to broach that are not part of this protocol, please bring them with you to your appointment.

1. Tell me a little about your life history; particularly the parts that you either remember the most or think are the most important.
2. When in your life have you felt most alive?
3. Are there particular things that you are hoping for your family to know or learn about you?
4. What are the most important roles you have played in your life thus far (e.g. family roles, vocational roles, community service roles, etc.)? Why were they so important to you, and what do you think you accomplished within these roles?
5. What are your most important accomplishments, and what do you feel most proud of or take most pride in?
6. Are there particular things that you feel the need to pass on to your loved ones or things that you would like to take the opportunity to say once again?
7. What are your hopes and dreams for your loved ones?
8. What have you learned thus far about life that you would like to pass along to others? What advice or words of guidance would you wish to pass along to your loved ones?
9. Are there important words, or perhaps even instructions, you would like to take the opportunity to offer your family?
10. In creating this permanent record, are there other things that you would like included?

Seeking Research Participants

We are currently recruiting research participants who might be interested in engaging in a novel form of therapy called Dignity Therapy.



What would my involvement look like?

- You would first be provided with more information about the study and given a chance to ask questions over the phone with a researcher on the study.
- You would be asked to come to XXXX for 3 in-person research sessions:
 - o At the first session, you will have an opportunity to review the consent for the study, ask questions, and sign the consent document indicating that you have had your questions answered. This visit will last about 30 minutes.
 - o At the second session, you would engage in an audio-recorded Dignity Therapy interview with the researcher. This visit will last about 2 hours.
 - o At the third session, you would help edit the transcription of your interview and then answer some questions about your experience of participating in the interview. This visit will last about 2 hours.

Who is eligible to participate in this study?

- You must be at least 18 years of age.
- You must be fluent in English.
- You must be within 30-60 days post transplant.
- You must be able to commit to the three in-person research visits at XXXX over the course of one to two weeks.

What is Dignity Therapy?

- Dignity Therapy is a narrative based psychotherapy intervention used to reduce levels of existential distress in those who are facing life threatening or life limiting illnesses.
- You will be asked to participate in a Dignity Therapy interview with the researcher and then answer some questions about your experience.

Are there any risks or benefits to participating in the study?

- There are no known risks for participating in this research study.
- At the completion of your participation, you will receive a copy of your transcribed Dignity Therapy interview.

If interested, please contact Emily Newman, M.A. at xxx-xxx-xxxx

(Name of the psychosocial team member) tells me that you are interested in participating in the Dignity Therapy research project. I'd like to tell you a little bit about it and answer any questions you might have. Dignity Therapy is a talking therapy that has been specially designed to help people who are living through significant medical challenges. There have been many studies done on Dignity Therapy and the results indicate that it can help many people cope, improve how they feel about themselves and their circumstances, and even improve their quality of life. Dignity Therapy usually takes about three in-person sessions and it gives people a chance to talk about things that are most important to them, things that they may want to share with those they are closest to, and things that they want to take the opportunity to say. These conversations are audio recorded, transcribed, and edited. The final product is a type-written document on paper, which is returned to you and can be shared with your family if you choose. Most people find the experience very meaningful and find comfort in knowing that the document is for them to keep and something they can share with the people they care about. This research project is hoping to see if Dignity Therapy may be a helpful intervention for people who have undergone allogeneic blood or marrow transplants, as this has not yet been studied. What questions do you have for me at this time?

Demographic Information

This information is being collected to provide a context for the Dignity Therapy interview material as well as to gauge preconceptions of the Dignity Therapy protocol.

Please fill out the following information to the best of your knowledge.

1. Please write your full name_____
2. How would you like to be addressed? _____
3. What is your date of birth?_____
4. What is your marital status?_____
5. Who is currently living with you in your home (including pets)?_____
6. Do you have any children? (please circle) yes/no
a. If yes, what are their ages?_____
7. Do you have any grandchildren? (please circle) yes/no
a. If yes, what are their ages?_____
8. What is your employment status?_____
9. What is/was your most recent job?_____
10. How many days are you removed from your bone marrow transplant?_____
11. Please describe the duration and nature of your illness.

12. Please describe your understanding of the seriousness of your condition.

13. Please describe ways in which you have coped with your illness and treatment thus far.

14. What are you hoping to accomplish by doing Dignity Therapy?

15. Following the transcription and editing of your interview, I will mail you a copy of your generativity document. Please provide me your home address?

Appendix E

Participant Feedback Questionnaire

Participant code number:

We would appreciate your feedback and impressions of the Dignity Therapy. Please answer the following questions:

1. I have found the Dignity Therapy to be helpful to me.

Strongly	Disagree	Neither Agree	Agree	Strongly Agree
Disagree		nor Disagree		

What are your reasons for that opinion?

2. I have found the Dignity Therapy to be satisfactory.

Strongly	Disagree	Neither Agree	Agree	Strongly Agree
Disagree		nor Disagree		

What are your reasons for that opinion?

3. The Dignity Therapy made me feel that my life currently is more meaningful.

Strongly	Disagree	Neither Agree	Agree	Strongly Agree
Disagree		nor Disagree		

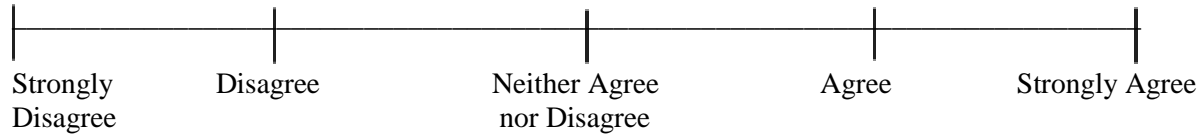
What are your reasons for that opinion?

4. The Dignity Therapy has given me a heightened sense of purpose.

Strongly	Disagree	Neither Agree	Agree	Strongly Agree
Disagree		nor Disagree		

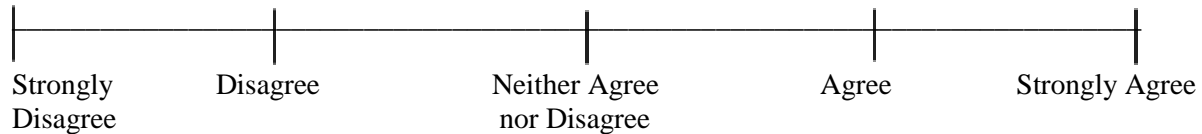
What are your reasons for that opinion?

5. The Dignity Therapy has given me a heightened sense of dignity.



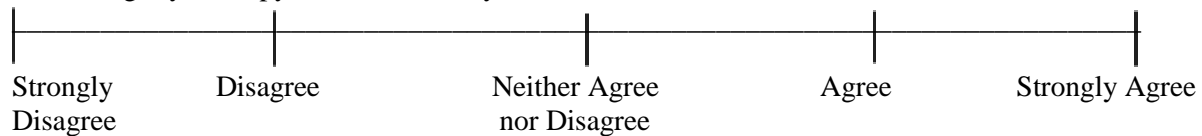
What are your reasons for that opinion?

6. The Dignity Therapy has lessened my sense of suffering.



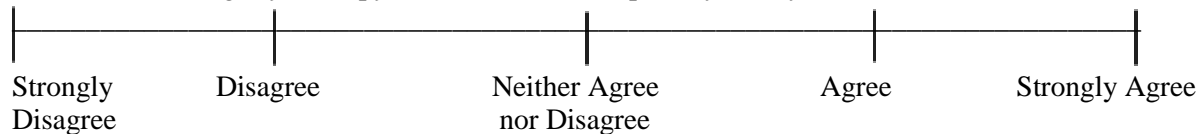
What are your reasons for that opinion?

7. The Dignity Therapy has increased my will to live.



What are your reasons for that opinion?

8. I believe the Dignity Therapy has or will be of help to my family.



What are your reasons for that opinion?

9. I believe my participation in the Dignity Therapy could change the way my family sees or appreciates me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

What are your reasons for that opinion?

10. I believe my participation in the Dignity Therapy could change the way my health care providers see or appreciate me.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

What are your reasons for that opinion?

11. In general, I have been satisfied with my psychosocial care.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

What are your reasons for that opinion?

Any other comments regarding your experience of the Dignity Therapy, and how you think it might be improved, would be most appreciated.

Thank you for completing this questionnaire.